

# Caregiver Diversity

More than 7 million people are informal caregivers of elders— family members or friends who care for loved ones who are ill or have disabilities and live at home. There are wide variations in the conditions of those who are receiving help, the kinds of assistance needed, the level of caregiver burden, and the self-perceptions of caregivers. Caregivers come from all ethnic and racial backgrounds.

African American, Asian American, and Hispanic American households tend to be more involved in caregiving than the general population. In addition, the proportion of minority family members involved in caregiving is higher than those in non-minority families, particularly among adult children. The National Academy on an Aging Society found that adult children account for the largest proportion of caregivers. A partial profile of caregivers shows that:

- Spouses account for 28 percent of the caregivers of white elders, 20 percent among Hispanic Americans, and 15 percent among African American elders:
- More than 52 percent of Hispanic Americans receive care from adult children, while smaller proportions of African-American and white elders receive help from their adult children; and
- African-Americans are most likely to receive care from non-relatives.

## Working to Meet the Needs of Diverse Families

Diversity presents caregivers and the aging network with unique challenges. For example, due to differences in language and cultural beliefs and discrimination, minority families often have difficulties in or are reluctant to access information and services to which they are entitled. In addition, culture shapes both individual and group values and attitudes, including perceptions about what works and what doesn't work, what is helpful and what is not, what makes sense and what does not. Realizing this, the U.S. Administration on Aging (AoA) is striving to improve access to quality services by working with communities to offer culturally sensitive programs and services.

## National Family Caregiver Support Program

The National Family Caregiver Support Program aims to help families sustain their efforts to care for an older relative who has a serious chronic illness or disability. Under the Program, all states, working in partnership with area agencies on aging, offer five basic sets of services for family caregivers including:

- Information about resources to help families in their caregiver roles;
- Assistance to families in locating services from a variety of private

and voluntary agencies;

- Caregiver counseling, training and peer support to help these families to better cope with the emotional and physical stress of dealing with the disabling effects of a family member's chronic condition;
- Allowing for respite care provided in a home, and adult day care center or over a weekend in a nursing home or residential community such as an assisted living facility; and
- Providing limited supplemental services to complement care provided by eligible caregivers to individuals needing help with at least two activities of daily living or requiring substantial supervision because of a cognitive or mental impairment.

Priority will be given to older individuals with the greatest social and economic need and older individuals providing care and support to persons with mental retardation and related developmental disabilities.

#### Alzheimer's Disease Demonstration Grants to States Program

Mental health concerns are a priority for AoA. AoA supports a successful demonstration program designed to expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families and caregivers. Projects demonstrate the effective coordination and use of existing public and private resources within states to enhance educational efforts and service delivery systems for this population. In June 2000, new grants were delivered to 16 states to develop models of care for persons with Alzheimer's disease and to improve the responsiveness of the home and community-based care system for persons with dementia. Projects are targeted to hard-to-reach populations including ethnic minorities, low-income and rural families with Alzheimer's disease.

#### **Future Challenges**

Diversity presents everyone – especially those involved in the aging network – with a unique set of challenges and opportunities. A specific challenge is to provide critical information to minority caregivers, some of whom may speak languages other than English. Projected increases in the minority population, coupled with their distinct, varying cultures have ramifications for caregiver support programs. Those involved in providing services to diverse caregivers must become familiar with issues related to race, culture, and ethnicity and how they can affect caregiver beliefs and practices.

Our aim must be to provide the <u>right</u> services in the <u>right</u> ways and to the <u>right</u> persons at the <u>right</u> time in the <u>right</u> settings. To help accomplish those goals, AoA provides the following suggestions:

- People: Community and consumer participation is key. Find community members who are respected and valued. Maximize your investment – use volunteers. Train the front line: a culturally competent staff is a more effective staff.
- **Places:** Go to your target audience. Identify places that are natural sites for the group you want to reach. Be creative.
- Process: Update communications styles. Use sensitivity. Seek greater knowledge. Find alternatives to written communication. Use material reflective of the community.
- Pathways: Values and attitudes matter. Promote mutual respect.
   Use a client-centered perspective. Know this: belief systems influence behavior and community involvement.

Working together, AoA is confident we can meet the challenges and maximize the opportunities posed by population diversity in the 21<sup>st</sup> century.

Working in close partnership with its sister agencies in the U.S. Department of Health and Human Services, the AoA is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers. The AoA works through the national aging network of 56 State Units on Aging, 655 Area Agencies on Aging, 233 Tribal and Native organizations representing 300 American Indian and Alaska Native Tribal organizations, and two organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers. For more information about the AoA, please contact:



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